

# Leeds Health & Wellbeing Board

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**Report of:** Chief Officer Health Partnerships and Chair Leeds Informatics Board

**Report to:** Leeds Health and Wellbeing Board

**Date:** 25 March 2015

**Subject:** Joined Up Leeds

Are there implications for equality and diversity and cohesion and integration?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Is the decision eligible for Call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

## Summary of main issues

Leeds has a vision to be the best city for health and wellbeing, and to be global leader for health innovation. Using information appropriately is an important component to support this ambition. Missing opportunities to do so might hinder the city's ability to improve health outcomes and reduce inequalities.

The different organisations and departments that make up the NHS and Council in Leeds hold a lot of information about local citizens. People who look after our health and wellbeing don't always get the full picture of how they can help us, and opportunities to appropriately use, share and release information to improve services may be missed. In order to support data-sharing initiatives in Leeds (e.g. the Leeds Care Record, Summary Care Records, and the Leeds Data Mill), the NHS and Council want to get a better understanding of what people think and feel about how their information should be used.

'Joined Up Leeds' is a citywide conversation between the public sector and the people of Leeds, which encouraged citizens to think and talk about information sharing, its benefits, and concerns. We then gathered and analysed people's views during the conversations.

**The initial research findings tell us that most citizens are willing for information about them to be used to improve health and wellbeing in Leeds and to plan services. This includes granting wider access to personal medical records, publishing information on the number of people with different conditions and situations (aggregated data) and releasing datasets that contain anonymous information about them (open data).**

Please see later in the report for further highlighted findings (section 3.1). The full set of results will be made available once the final report is completed, due 25 March 2015.

## **Recommendations**

The Health and Wellbeing Board is asked to:

- Read the full set of results from the Joined Up Leeds research on citizens' views on information sharing, and in particular, the section on what would reassure citizens about how their information is used, when made available on 25 March 2015.
- Promote the individual data-sharing initiatives in the city, as there is clear support from citizens for using information to better plan services and deliver more seamless health and social care.
- Support any future initiatives to enable citizens to take a greater role in owning their health and social records.
- Encourage further conversations and engagement in the city about the concept of information sharing. Joined Up Leeds should be seen as the start of exploring how sharing information could help to improve health and wellbeing for citizens within Leeds.
- Use the findings and further engagement initiatives to create and deliver a data sharing framework for the city.

### **1 Purpose of this report**

- 1.1 Leeds Health and Wellbeing Board is committed to engaging with patients and the public in the co-production of health and social care services – and information sharing is no exception. There has been a lot of support locally from organisations that work with health and social care data to start an open, transparent and public discussion about the use of this data. It is important that we understand the views of our citizens about the concept, benefits and perceived risks of sharing their information.
- 1.2 This will then be used to create an information sharing framework to be clear about why we will share information. It should be noted, that this report does not address how information is shared or stored, nor does it seek to comment on the legal basis for doing so.

1.3 This report describes the activities that formed 'Joined Up Leeds' and we will be able to provide a summary of the findings at the Health and Wellbeing Board on 25 March 2015.

## **2 Background information**

2.1 Residents of Leeds have the benefits of accessing health and social care services. The organisations delivering such services include our GP Practice, our local hospitals, community nurses and local social care services teams. To deliver services, these organisations collect information about us. They also share information about people with each other as deemed appropriate by the health and social care professionals involved in care. Citizens know that the world of data and information is changing. People may sign up for 'Google' or 'Apple' services or see on-line adverts targeted at them because of a shopping web site they may have been browsing. Consumers may choose to interact with and bank on-line. We hear worrying headlines about security systems being breached. We hear about information being used for research and are unsure whether our personal data can be identified.

2.2 In Leeds, we want residents to be given the best possible health and social care. We also want those services to be improved over time by learning from the past and anticipating the future. This includes analysing information. People differ in how much they want to engage in information sharing. For example, some people collect data for their own health and fitness and would like to share it with their doctor, whereas others would not. Organisations in Leeds that currently handle health and social care data would like to understand how citizens feel about how their information is used now and might be used in the future and how residents of Leeds can be involved and engaged with this.

2.3 The Joined Up Leeds conversation was undertaken to encourage people to think and talk about how information about them could be used by the NHS and the council to improve health and wellbeing in the city. Their views can then inform the future information-sharing approach developed in Leeds.

2.4 The project had three stages:

- The first was to interview key thinkers on data sharing in the city and to use this to develop materials to help citizens understand how information could be used, and the risks and benefits of doing so.
- The second stage was to hold a variety of conversations with people in Leeds and to encourage them to contribute their views.
- The third was to analyse the data collected and to develop recommendations for how information sharing in the city should develop.

2.5 Interviews with key thinkers on information sharing in the city were undertaken to explore their views and experiences of data sharing and their ideas for the future. A literature review on patient beliefs on greater sharing of their medical records

was also undertaken. The insight gained was used to develop a set of materials that could be used to help citizens understand some of the potential benefits and risks of information sharing and to get them talking about how information is used in their day-to-day lives and how it could be better used for health and wellbeing in the future.

### **3 Main issues**

3.1 Joined Up Leeds is a conversation with the citizens of Leeds to encourage them to discuss information sharing and the following findings have become evident during the activity:

- Most citizens are willing for information about them to be used to improve health and wellbeing in Leeds and to plan services. This includes granting wider access to personal medical records, publishing information on the number of people with different conditions and situations (aggregated data) and releasing datasets that contain anonymous information about them (open data).
- Individual citizens should not be identifiable from information released about them. They do not want to be contacted or marketed to as a consequence of their information being released.
- Citizens want to feel in control of who has access to their information, particularly their individual medical records. They need to trust people who see information about them.
- It should be possible for citizens to opt out of information sharing, although they need to understand the implications for themselves and others of doing so.
- Let citizens know – in easy-to-understand terms – what the information collected from them is being used for. This should not be hidden in terms and conditions.
- Help citizens to understand the value of information by developing clear examples of how information about citizens has been used to improve services.
- The cost of making datasets available should be less than the financial savings made from better and more efficient services.
- People analysing open data should not release sensationalised, inaccurate or misleading stories to the media.
- People using information to make decisions about citizens should remember that they are people, not numbers.
- There were no statistically significant differences in beliefs expressed by people living in Inner East, Inner West and Inner South Leeds and those in other areas of the city.

The full results will be available in a report on 25 March 2015.

- 3.2 It was important to make it easy for citizens to get involved and contribute their views, and so several different ways of joining the conversation were developed. These included citywide workshops, small group discussions, event cards, online conversations using Facebook [[www.facebook.com/joinedupleeds](http://www.facebook.com/joinedupleeds)], blogs <https://joinedupleeds.wordpress.com>, Twitter #JoinedUpLeeds, an online survey, invitations to host workshops and more. People were also invited to email the researchers directly with comments and questions. Providing different opportunities for citizens to engage with the conversation encouraged a wide variety of people to be involved in a way that was relevant to them.
- 3.3 Joined Up Leeds has been a great example of collaborative working across the city – Leeds City Council, NHS partner organisations and Healthwatch Leeds were involved to help promote the conversation.
- 3.4 There was a delay in issuing the online survey via the Citizens Panel, which meant that we missed the benefit of promoting Joined Up Leeds during the two week burst of activity. However the response to the survey has exceeded the target. Some politicians were engaged directly whilst others were given the opportunity to do so through workshops.
- 3.5 Leeds City Council and NHS communication teams provided excellent support throughout and a substantial impact was created within the planning, build up and two weeks of conversation. The following was achieved:
- 17 events took place attended by 157 people. They took place across various locations, times and days of the week.
  - 185 chat packs downloaded
  - 187 event cards completed
  - 1073 surveys completed
  - 111 likes on Facebook
  - Over 8,000 people reached on Facebook
  - 492 tweets from 167 participants
  - Over 1.1 million impressions on twitter
  - Promotion in newsletters, blogs, press and Linked In
- 3.6 Similar projects have been criticised in the past because of limitations on types of venue used, therefore the research specifically targeted pubs, cafes, community and leisure centres where people gather and chat. Key influencers on both a local and national level, including those previously known to be critical of such initiatives, have praised the project publicly.

## **4 Health and Wellbeing Board Governance**

### **4.1 Consultation and Engagement**

- 4.1.1 The Joined Up Leeds conversation is based on involving many and diverse citizens in discussing how their health and social care data could and should be shared, the benefits of sharing, the concerns they have, and how data could be

used for the benefit of people in Leeds. It is an exchange of information, or a “conversation” between the authorities and experts who want to share and use health and social care data and the citizens of Leeds themselves. It involved awareness-raising activities (based on presenting case studies) to generate interest and enthusiasm in the debate and to enable people to have an informed discussion about data sharing.

- 4.1.2 The many different ways that citizens could participate in Joined Up Leeds ensured a wide range of Leeds citizens took part and it’s approach has been seen as innovative due to the variety of channels that people could engage via. The open events and event cards helped to open up the conversation to younger people because of the venues they were held in.
- 4.1.3 The success of the conversation was due to the collaborative approach from NHS, Leeds City Council and Healthwatch Leeds and has demonstrated that when we use each partner organisations’ networks we can reach large sections of the public in Leeds.

## 4.2 **Equality and Diversity / Cohesion and Integration**

- 4.2.1 Joined Up Leeds hosted many events across the city, including affluent suburbs and areas where deprivation is more wide spread. Extra efforts were taken to involve people living in the Inner East, West and Inner South areas of Leeds. There were no statistically significant differences in beliefs expressed by people living in Inner East, Inner West and Inner South Leeds and those in other areas of the city. Joined Up Leeds has been praised for taking the conversation to where people talk rather than relying on NHS and council buildings to host events. Pubs, cafes, care homes, and piggybacking on community events proved that we could reach a wider community instead of speaking to the usual faces that are already engaged in public service debates.

## 4.3 **Resources and value for money**

- 4.3.1 Being explicit about views on information leads to better decision making by staff and better value for money. Using an external market research agency to facilitate the Joined Up Leeds conversation has allowed for independence in the results generated.

## 4.4 **Legal Implications, Access to Information and Call In**

- 4.4.1 There are no legal implications arising from this report; it is not subject to call in.

## 4.5 **Risk Management**

- 4.5.1 Raising awareness about the information sharing approach may result in people opting out of Leeds Care Record, Summary Care Records and other data intelligence-led projects. To mitigate this risk a series of case studies were developed for Joined Up Leeds that highlighted the potential benefits of

information sharing. These were used at the start of conversations so that people could have informed discussions, share their thoughts, concerns or ideas for the future. Failure to share information appropriately and missing opportunities to do so might hinder the city's ability to improve outcomes and reduce inequalities.

## **5 Conclusions**

Joined Up Leeds is a successful collaborative project that encouraged citizens to think and talk about how their information could be used to help improve health and wellbeing. Once the full set of results is made available it should help inform a future information-sharing framework for Leeds that is mindful of national data sharing initiatives but that people feel they have been involved in.

## **6. Recommendations**

6.1 The Health and Wellbeing Board is asked to:

- Read the full set of results from the Joined Up Leeds research on citizens' views on information sharing, and in particular, the section on what would reassure citizens about how their information is used, when made available on 25 March 2015.
- Promote the individual data-sharing initiatives in the city, as there is clear support from citizens for using information to better plan services and deliver more seamless health and social care.
- Support any future initiatives to enable citizens to take a greater role in owning their health and social records.
- Encourage further conversations and engagement in the city about the concept of information sharing. Joined Up Leeds should be seen as the start of exploring how sharing information could help to improve health and wellbeing for citizens within Leeds.
- Use the findings and further engagement initiatives to create and deliver a data sharing framework for the city.